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## **1500 INDIVIDUAL RIGHTS AND RESPONSIBILITIES**

### **1501 Overview**

This chapter presents the Division of Developmental Disabilities' (Division's) policies regarding the rights and responsibilities of individuals with developmental disabilities. The Division is especially concerned with protecting the rights of all individuals who are receiving supports and services operated by, licensed and supervised or financially supported by the Division. The chapter discusses basic human and disability-related rights and responsibilities; Human Rights Committees; informed consent of individuals receiving supports and services and Advance Directive/Living Will in Arizona. Mention of specific rights in this chapter is not meant to be all inclusive.

### **1502 Basic Human and Disability Related Rights**

Arizona Revised Statutes clearly recognize that an individual with a developmental disability has the rights, benefits and privileges guaranteed by the Constitutions and laws of the United States and the State of Arizona.

The Division Mission and Value Statement, presented in Chapter 200 of this Manual, makes clear that individuals with developmental disabilities have the right to expect programs, supports and services which develop, enhance and support environments that enable them to achieve and maintain physical well-being, personal and professional satisfaction, participation as family and community members and safety from abuse and exploitation. In support of this Mission and as a means of ensuring that the rights of an individual with a developmental disability are protected, the Division has adopted various rules which are part of the Arizona Administrative Code.

Thus, the rights of an individual with a developmental disability who is receiving supports and services through the Division are protected by the federal Constitution, the State Constitution, federal and State laws, and policy and procedure manuals of various government entities.

The rights of an individual with a developmental disability receiving supports and services through the Division include but are not limited to:

- a. right to an initial Individual Support Plan prior to receiving supports and services;
- b. right to participate in the initial placement evaluation, periodic evaluations and whenever possible the opportunity to select among appropriate alternative supports and services;
- c. right (if accepted for supports and services) to participate in, share in decision making and receive a written Individual Support Plan based upon relevant results of the placement evaluation
- d. right to information regarding the supports and services available through a provider and about related charges, including any fees for supports and services not covered by a third-party payor;
- e. right to a periodic review of the Individual Support Plan;
- f. right to be given written notice of his/her rights;
- g. right to exercise his/her rights as citizens;
- h. right to live in the least restrictive setting;
- i. right to protection from physical, verbal, sexual or psychological abuse or punishment;
- j. right to equal employment opportunity;
- k. right to fair compensation for labor;
- l. right to own, rent or lease property;
- m. right to marry and have children;
- n. right to be free from involuntary sterilization;
- o. right to express human sexuality and receive appropriate training;

- p. right to consume alcoholic beverages if 21 years of age or older unless contraindicated by orders of his/her primary care physician;
- q. right to presumption of legal competency in guardianship proceedings;
- r. right to be free from unnecessary and excessive medication;
- s. right to be accorded privacy during treatment and care of personal needs;
- t. right to confidentiality of information and medical records;
- u. right of a school-age individual to receive publicly-supported educational services;
- v. right of a child to receive appropriate supports and services, subject to available appropriations, which do not require the relinquishment or restriction of parental rights or custody except as prescribed in Arizona Revised Statutes § 8-533 which describes the grounds needed to justify the termination of the parent-child relationship;
- w. right to consent to or withhold consent from participation in a research project approved by the Division management team or any other research project; right to knowledge regarding the nature of the research, potential effects of a treatment procedure as part of a research project; right to confidentiality; and the right to withdraw from the research project at any time;
- x. right of an individual who believes his/her rights have been violated to petition the Superior Court for redress unless other remedies exist under federal or State laws;
- y. right to withdraw from programs, supports and services, unless the individual was assigned to the Department by the juvenile court or placed in a secure facility by the guardian and court;

- z. right to an administrative review, if in disagreement with a decision made by the Division (by filing a written request for such with the Division Office of Compliance and Review and the right to appeal the decision (see Chapter 2200); and
- aa. right to contact the Human Rights Committee.

United States Code, Annotated 42-12010, et seq.  
Arizona Revised Statutes § 41-1492, et seq.  
Arizona Revised Statutes § 36-554(A)(10)  
Arizona Revised Statutes § 36-551(01)(0)  
Arizona Revised Statutes § 36-568(01)  
Arizona Revised Statutes § 41-1959  
Arizona Administrative Code R6-6-104  
Arizona Administrative Code R6-6-102(C)  
Arizona Administrative Code R6-6-901-910  
Arizona Administrative Code R6-6-102(C)  
Arizona Administrative Code R6-6-1801, et seq.  
Arizona Administrative Code R6-6-2002-2003

1502.1 The Rights of Individuals with Developmental Disabilities Living in Residential Settings

The rights of individuals with developmental disabilities who reside in residential settings such as group homes, adult and child developmental homes or an Intermediate Care Facility for the Cognitive Disabled include the basic human and disability-related rights listed previously, however, because of the special circumstances of living in a residential facility, specific rights have been delineated below.

These rights include, but are not limited to:

- a. right to be informed of the rules of the residential setting in which he/she is living;
- b. right to impartial access to treatment and/or accommodations;
- c. right to a humane and clean physical environment;

- d. right to communicate with those responsible for his/her care;
- e. right to choose his/her personal care physician from the health plan(s) available;
- f. right to be informed of his/her medical condition, of any technical procedures that will be performed, of the identity of the persons who will perform the procedures, attendant risks of treatment and the right to refuse treatment;
- g. right to be free from unnecessary drugs and physical restraints, except as authorized in writing by a physician for a specified time period and in accordance with the Division rules regarding behavior modification (See Chapter 1600);
- h. right to a physical examination, prompt medical attention and to adequate food and water;
- i. right to his/her own bed;
- j. right to personal clothing and possessions as space permits, unless this infringes on the rights of others or is medically contraindicated;
- k. right to be accorded privacy with regard to written correspondence, telephone communication and visitors;
- l. right of a husband and wife who both reside in a facility to share a room;
- m. right to privacy during visits by a spouse;
- n. right to refuse to talk with or see someone;
- o. right to participate in social, religious and community group activities;
- p. right to manage his/her own financial affairs and to be taught to do so to the extent of his/her capabilities;

- q. right to refuse to perform services for the facility, but if he/she does provide services, right to be compensated at prevailing wages commensurate with his/her abilities;
- r. right to have the Division supervisors advised of any unusual incident that occurs; and
- s. right to file a grievance not only with the Division but also with his/her health plan, ALTCS and AHCCCS.

42 Code of Federal Regulations Part 438.420(a)  
Arizona Administrative Code R6-6-901, et seq.  
Arizona Administrative Code R6-6-107  
ALTCS Program Management Manual

#### 1502.2 Individual Rights Upon Reaching Legal Age

When an individual with a developmental disability reaches his/her legal age (18 in Arizona except for drinking alcohol which is age 21) he/she has the following rights:

- a. right to register and vote;
- b. right to create and maintain financial contracts;
- c. right to sue and to be sued;
- d. right to counsel;
- e. right to be prosecuted as an adult; and
- f. right to choose to continue receiving supports and services or to terminate supports and services; thus residency in any residential setting is voluntary.

#### 1502.3 Limitations of Rights

Rights guaranteed by the Arizona Revised Statutes and the Arizona Administrative Code may be restricted or suspended by court action, e.g., the establishment of a legal guardian or the requirement of supervised visitations with natural parents, or as part of an approved Individual Support Plan, e.g., requirement to be accompanied by a responsible adult when going on an outing if the individual lacks the necessary skills for doing so alone.



1502.4      Responsibilities of Individuals Applying for and/or Receiving Supports and Services

Individuals/responsible persons applying for and/or receiving supports and services, have certain responsibilities. Responsibilities of individuals receiving supports and services include but are not limited to:

- a. responsibility to cooperate with the Division staff by providing required information relative to personal information required on the application; when accepted for supports and services the individual is responsible for informing his/her Support Coordinator of any change in such data;
- b. responsibility to participate in the development of his/her Individual Support Plan and to signify agreement or disagreement by signing the Individual Support Plan;
- c. responsibility to assign to the Division rights to first party health insurance medical benefits to which the individual is entitled and which relate to the specific supports and services which the person has received or will receive as part of his/her Individual Support Plan; and
- d. responsibility to uphold all laws of local, State and federal bodies.

Individuals/responsible persons applying for and/or receiving supports and services through ALTCS also have certain additional responsibilities. These responsibilities include but are not limited to:

- a. responsibility for providing accurate and complete information regarding his/her health history;
- b. responsibility for reporting unexpected changes in his/her health status;
- c. responsibility for following the treatment plan or the responsibility for his/her actions if treatment is refused or not followed as prescribed;

- d. responsibility for being considerate of the rights of other residents and facility personnel in regards to personal behavior, control of noise and number of visitors; and
- e. responsibility for being respectful of the property of others and of the facility.

Arizona Revised Statutes § 36-596(B)  
Arizona Administrative Code R6-6-401  
Arizona Administrative Code R6-6-603  
ALTCS Program Management Manual

#### 1502.5      Procedures

The following summarizes some of the major tasks of a Support Coordinator relative to protecting the rights of individuals receiving supports and services through the Division:

- a. during the intake process, the Support Coordinator must explain to the individual/responsible person his/her rights and give him/her a printed copy of PAD-195, Statement of Rights (Appendix 1500.A). The individual/responsible person must sign a statement indicating that he/she has received a copy of these rights and that they have been explained to him/her (Appendix 1500.A). One copy of the statement must be placed in the individual's file and a second copy of the statement must be given to the individual/responsible person;
- b. as part of the initial Individual Support Plan, the Support Coordinator must verify that the individual has been provided a copy of his/her rights and responsibilities, that these rights and responsibilities have been explained, and the individual/responsible person has so acknowledged; if this has not occurred, it shall be incorporated into the initial Individual Support Plan;
- c. the Support Coordinator will assist individuals as necessary or as requested in applying for ALTCS and in filing a grievance and/or a request for an administrative review;

- d. the Support Coordinator will follow-up on any report that an individual's rights have been violated by filing an incident report with the District Program Manager/Administrator; and
- e. at the Individual Support Plan team meeting prior to or after an individual becomes of legal age, whichever is closer in time, the Support Coordinator shall:
  - 1. remind the Individual Support Plan team of the date on which the individual will become of legal age; and
  - 2. inform the individual/responsible person verbally of his/her "new" legal rights (See Section 1502.2).

#### 1502.6 District Human Rights Committees

Human Rights Committees are groups of local citizens who provide independent oversight in matters related to the rights of individuals with developmental disabilities who are served by the Division. Each Human Rights Committee must meet at least six times each calendar year, but as often as necessary as determined by the chair in accordance with the bylaws of the committee. Specifically, the Human Rights Committee reviews the rights of individuals in the following areas:

- a. administration of medication which changes recipient's behavior either directly or as a side effect;
- b. aversive or intrusive programs;
- c. research proposals in the field of developmental disabilities which directly involve individuals receiving supports and services; and
- d. incidents of possible abuse, neglect or violations of an individual's rights.

Any suspected violation of rights of an individual with developmental disabilities should be identified to the appropriate Human Rights Committee.

In addition to the protection of rights of individuals, the Human Rights Committee must:

- a. submit in writing to the Division Assistant Director any objections it has to actions by employees of the Division or employees of service providers; and
- b. issue an annual report summarizing its activities and making recommendations of changes it believes the Division should consider implementing.

There are several Human Rights Committees in the State, each serving one or more counties. For further information on the Human Rights Committee in your area, contact your District Administrative Office (Appendix 100.A).

Arizona Administrative Code R6-6-1701, et seq.

#### 1502.6.1 Membership in Human Rights Committees

Membership in Human Rights Committees shall occur utilizing the following process:

- a. candidates for initial membership on a newly developed committee shall be recruited by the District Program Manager/Administrator with input and advice from the local Arc, Developmental Disabilities Advisory Council and any other appropriate local advocacy organizations. The Director of the Department shall appoint committee members from the list of candidates recruited locally;
- b. each committee shall be comprised of at least seven (7) and not more than 15 persons with expertise in one or more of the following areas:
  1. psychology;
  2. law;
  3. medicine;
  4. education;
  5. special education; and
  6. parents of people with developmental disabilities.

- c. no employee of the Department or of a service provider which is associated with an existing Human Rights Committee may be a voting member of a committee; and
- d. when there is a vacancy in an existing committee's membership, nominees may be presented to the committee by advocacy groups, committee members or the District Program Manager/Administrator. Upon recommendation by the committee, by at least a majority vote, the Director shall appoint a person to fill the vacancy.

Arizona Administrative Code R6-6-1702

1502.6.2      Reporting Information to Human Rights Committees

The Division will provide the following to Human Rights Committees:

- a. Incidents of possible abuse or neglect;
- b. Violations of rights;
- c. Administration of medication which changes the individual's behavior either directly or as a side effect;
- d. Aversive or intrusive programs;
- e. Client intervention techniques for medical treatment, i.e., a medical or dental appointment;
- f. Research proposals in the field of developmental disabilities which directly involve individuals receiving supports and services;
- g. All behavioral emergency measures as stated in Arizona Administrative Code R6-6-901, et seq.;
- h. Copies of residential monitoring compliance reports and summaries of homes monitored in the area along with corrective action plans;
- i. Copies of all Individual Support Plans in which the team has not reached consensus, as requested by any member of the team;

- j. Copies of Serious Incident Reports and resulting investigations involving the Division;
- k. Copies of “substantiated/unsubstantiated” reports from Adult Protective Services and Child Protective Services;
- l. Theft of client property and money;
- m. Medication errors including theft or missing medications;
- n. Incidents and circumstances that pose a threat to the physical or emotional well-being of an individual or staff member;
- o. Property damage/destruction;
- p. Notification (within 24 hours) of serious incidents, i.e., death, violation of rights;
- q. Reports of special investigations received by the Division; and
- r. Copies of provider investigations, subsequent analysis of report findings and corrective action plans.

All Human Rights Committee Members shall sign a confidentiality statement each year. Re-disclosure of confidential information is prohibited.

### **1503 Informed Consent**

As one means of protecting the rights of individuals receiving supports and services, the Division requires written consent from the individual/responsible person for release of confidential information and for participation in events, treatments and activities. Arizona Revised Statutes § 36-551(11) defines consent as voluntary informed consent. Consent is voluntary if not given as the result of coercion or undue influence. Consent is informed if the person giving the consent has been informed of and comprehends the nature, purpose, consequences, risks and benefits of the alternatives to the procedure and has been informed and comprehends that withholding or withdrawal of consent will not prejudice the future provision of care and supports and services to the individual. In case of unusual or hazardous treatment procedures performed pursuant to Arizona Revised Statutes § 36-561, subsection A, experimental research, organ transplantation and non-therapeutic

surgery, consent is informed if, in addition to the foregoing, the person giving the consent has been informed of and comprehends the method to be used in the proposed procedure.

All consents must be time-limited. The maximum consent period is 12 months. Consent may be withdrawn at any time by giving written notification to the Division Support Coordinator.

#### 1503.1 Procedures

As a means of providing consistency in obtaining informed consent, the Division has developed specific forms for Support Coordinators to use in obtaining consent. These forms are printed in both English and Spanish. Consent forms are to be reviewed annually as part of the Individual Support Plan.

- a. DD-524 "Authorization to Release Information" (Appendix 500.E)

At the time of intake, the Support Coordinator shall obtain from the individual/responsible person a signature authorizing release of information necessary for determining the eligibility of the individual and/or for determining the supports and services needed by the individual. Form number DD-524 must be used for this purpose. Consents for evaluation, assessment and release of information related to intake and eligibility are only valid for 90 days from the date of signature; subsequent consents are valid for six (6) months;

- b. DD-162 "Consent for Use of Behavior-Modifying Medications with a Behavior Treatment Plan" (pages 1 & 2, Appendix 1500.C)

The Support Coordinator must have the individual's personal physician complete page 1 of this form indicating the reasons for prescribing the medication, expected benefits, probable side effects and precautions to be taken. The Support Coordinator sends a copy of the completed page 1 together with a copy of page 2 to the individual/responsible person. Section I of page 2 gives consent for the behavior-modifying medication; Section II of the form refuses consent. The individual/responsible person is to complete and sign either Section I or Section II and return the form to his/her Division Support Coordinator. The consent period must not exceed 12 months. (See also Chapter 1600);

c. DD-163 "General Consent and Authorization" (Appendix 1500.D)

This form provides the opportunity for the individual/responsible person to give or withhold consent for:

1. necessary emergency treatments;
2. routine medical care;
3. routine dental care;
4. use of sedation/restraint when prescribed by a physician for medical/dental purposes;
5. necessary educational, vocational, and therapeutic evaluations or assessments;
6. participation in routine recreational leisure activities; and
7. administration of over-the-counter medicines and ongoing medications, prescribed by a physician or dentist, not to exceed the maximum dosage.

Further, the form provides the opportunity for the individual/responsible person to give or withhold consent for release of the following information: medical records, educational, social, psychological, financial or other.

The individual/responsible person may indicate "No" on the form beside each area thus indicating that his/her signature must be obtained prior to the occurrence of such events or the release of information.

This general consent form should be reviewed and signed at the annual Individual Support Plan.



- d. DD-164 "Consent for Specific One-Time Medical Procedure" (Appendix 1500.E)

This form is to be completed by the residential staff and sent to the individual/responsible person. The form indicates the medical procedure the physician has determined needs to be completed and informs the individual/responsible person that the physician needs to have a signed consent form. The Support Coordinator will follow-up to be sure that consent for the procedure has been given or has been refused and will note this in the individual's case file.

- e. DD-164A "Notification for Specific One-Time Medical Procedure" (Appendix 1500.F)

This form, completed by the residential staff, notifies the individual/responsible person that the individual's personal physician has determined that a specific procedure is needed and describes the procedure. While this procedure does not require consent, this form notifies the individual so that if he/she wants additional information prior to the next appointment, he/she can call the physician.

- f. DD-165 "Special Event Consent" (Appendix 1500.G)

The residential staff completes this form when there is a special event and consent is required for an individual to attend. The form indicates the type of event and any special items needed such as special clothing, food, etc. The form provides spaces for the individual/responsible person to sign granting or withholding permission to attend.

Signed consent forms shall be retained by the Support Coordinator in the individual's case file, in the provider's file and at each site, as appropriate, where the individual receives supports and services.

Arizona Revised Statutes § 36-551(11)

1503.2      Consent to Medical Treatment of Incapacitated Adults

An adult cannot consent to medical treatment if he/she lacks the understanding or capacity to make or communicate responsible decisions. One of the duties of a guardian is to make reasonable efforts to secure medical services for a client of the Division who is his/her ward. If a permanent guardian is unavailable (due to death, resignation, etc.), Arizona law allows other identified individuals to sign the consent for medical treatment of an incapacitated adult.

- a.      in the following order of priority, these individuals may act as a surrogate to sign the consent for medical treatment of an incapacitated adult when no guardian is available:
  - 1.      the spouse of the incapacitated adult;
  - 2.      an adult child;
  - 3.      a parent;
  - 4.      a domestic partner (assuming the individual is not married and no other person has a financial responsibility for the individual);
  - 5.      a brother or sister; or
  - 6.      a close friend ("a close friend" means an adult who has shown special care and concern for the individual, who is familiar with the individual's health care views and desires and who is willing and able to become involved and act in the individual's best interest).

A health care provider is required to make reasonable efforts to locate these designated individuals. In order to assist the reasonable efforts of health care providers, the Division Support Coordinators should have available, at all times, a complete list of the names, addresses and phone numbers of these designated individuals who may be contacted for purposes of signing a consent for medical treatment. A copy of the list may be provided to treating medical personnel, as necessary, to assist them in locating a person authorized, by law, to sign a consent for medical treatment if a guardian is unavailable. If none of these individuals is available, the appointment of a public fiduciary by the court may be requested.

- b. any competent adult, who has a properly executed power of attorney from a guardian which delegates to that adult the guardian's power to sign a consent for medical treatment of his ward, may legally sign the consent. The power of attorney is valid for no more than six (6) months.
- c. in an emergency, if time allows, a temporary guardian may be appointed by the court to sign a consent for medical treatment or the court may immediately exercise the power to consent to medical treatment prior to notice and hearing. If no one is available to serve as a temporary guardian, the court may appoint the public fiduciary.
- d. when an immediate, life threatening emergency exists and there is neither time to get to court nor time to contact the individuals who may lawfully sign a consent, an attending physician, after consultation with a second physician, may make the health care treatment decision without a signed consent.
- e. the Division Support Coordinators cannot sign a medical consent for treatment of incapacitated adults.

Arizona Revised Statutes § 14-5101  
Arizona Revised Statutes § 14-5104  
Arizona Revised Statutes § 14-5310  
Arizona Revised Statutes § 14-5312  
Arizona Revised Statutes § 14-5602  
Arizona Revised Statutes § 36-3231

### 1503.3 Consent to Medical Treatment of Minors

The general rule is that the parent or guardian of a minor must provide written consent for medical treatment, however, Arizona law allows other individuals to provide consent to medical treatment of a minor when a parent or guardian is unavailable.

- a. an individual may consent to the medical treatment of a minor if the individual has a properly executed power of attorney from the minor's parent or guardian delegating the power to consent to medical treatment. The delegation of power may be for no more than six (6) months.
- b. if time allows, a temporary guardian may be appointed by the court to consent to medical treatment, but the authority of the temporary guardian is limited to six (6) months. Where no one is available to act as a temporary guardian, the public fiduciary may be appointed by the court.

- c. in cases of emergency, where a parent or guardian cannot be located after reasonably diligent effort, consent may be given by a person standing in loco parentis to the minor. "In loco parentis" means a person who takes the parent's place by undertaking temporary care and control of a minor in the absence of a parent. As a practical matter, for example, this might be an individual who is a relative, caregiver or teacher of the minor.
- d. if no one can be located who stands in loco parentis to the minor, a physician can determine that an emergency exists, that a parent or guardian cannot be located or contacted after reasonable diligent effort, then the physician can perform a surgical procedure on the minor if necessary to treat a serious disease, injury, drug abuse or to save the life of the minor.
- e. as a general rule, the Division Support Coordinators cannot sign a medical consent for treatment of minors except for children in foster care.

Arizona Revised Statutes § 14-5104  
Arizona Revised Statutes § 14-5207  
Arizona Revised Statutes § 14-5209  
Arizona Revised Statutes § 14-5503  
Arizona Revised Statutes § 14-5602  
Arizona Revised Statutes § 36-2271  
Arizona Revised Statutes § 44-133

## **1504 Advance Directives/Living Will**

Medical facilities receiving federal funds, e.g., hospitals and nursing facilities, are required as part of their admission policies to ask all adults if he/she has a health care directive, a living will or a health care power of attorney. The purpose is to provide the facility with necessary information regarding the wishes of the individual should a life threatening situation arise and the individual is unable to communicate his/her wishes. If the individual does not have any form of an advance directive, the facility shall offer the individual the opportunity to complete one.

The Division recognizes the right of an individual/responsible person to make decisions, upon consultation with his/her primary care physician, relative to the medical care he/she wishes to receive by completing:

- a. a pre-hospital medical care directive;
- b. a living will; and/or;

- c. a written health care power of attorney.

This policy does not interfere with the right of a parent or guardian of an individual under the age of 18 years to create a written health care directive. A health care provider with moral objections to a health care directive is obliged to cooperate with the directive or promptly transfer the responsibility for the individual's care to a provider who is willing to act in accordance with the directive. Appendix 1500.I details actions for lay and licensed medical personnel to take.

A pre-hospital medical care directive (Appendix 1500.H) allows an individual to direct the withholding of specific care by emergency medical and hospital personnel. Per statute, this directive is printed on an orange background and is either letter or wallet size.

A living will is a written statement which directs and controls the health care treatment decisions that can be made on an individual's behalf. A person may use a living will without a health care power of attorney or may attach a living will to his/her health care power of attorney. If the living will is not part of a health care power of attorney, it must be witnessed and notarized.

A health care power of attorney permits an adult to designate another adult individual(s) to make health care decisions on his/her behalf whenever the individual is unable to communicate his/her wishes. This designation must be made when the individual is of sound mind and free from duress; further, the designation must be in writing, signed, witnessed and notarized in order to be valid in Arizona.

A pre-hospital medical care directive, a health care directive, a living will and/or a written health care power of attorney, including the samples provided in the 1992 legislation, virtually replace what was generally referred to as a Do Not Resuscitate (DNR) order, however, an individual's primary care physician must also note a DNR order on the individual's medical chart.

Arizona Revised Statutes § 36-3202, et seq.

#### 1504.1 Procedures

The Support Coordinator will ask the individual/responsible person if he/she has a health care directive, a living will or a health care power of attorney. If the individual has completed one of these documents, the Support Coordinator will ask the individual/responsible person to provide a copy of same so that it becomes part of his/her case file.

If the individual does not have one of the documents mentioned above, but is interested in having one, the Support Coordinator will direct the individual/responsible person where to find information and sample copies (Appendix 100.A). The Support Coordinator also should encourage the individual/responsible person to consult with his/her primary care physician regarding these decisions.

Annually the Support Coordinator must note the existence of the health care directive, the living will, and/or the health care power of attorney and verify or update the information. Whenever possible, the Support Coordinator shall ensure that a copy of the health care directive or living will is sent with the individual when he/she is transferred to a health care institution.

## **1505 Health Insurance Portability and Accountability Act**

The Division of Developmental Disabilities (Division) will comply with all of the requirements of the Health Insurance Portability and Accountability Act, will protect the confidentiality of protected health information and will apply protections to how protected health information is used and disclosed. The Division shall reasonably safeguard protected health information from any intentional or unintentional disclosure that is in violation of the Health Insurance Portability and Accountability Act.

### **1505.1 Notice of Privacy Practices**

The Division is required to abide by the terms of the Notice of Privacy Practices (Appendix 1500.I). The Division may change the terms of the notice at any time. The new notice will be effective for all protected health information that the Division maintains at that time. You can obtain a copy of any revised Notice of Privacy Practices by accessing the Division's website at [www.de.state.az.us/ddd](http://www.de.state.az.us/ddd) or requesting a copy from the Division's Privacy Officer.

An individual/responsible person has a right to adequate notice of the uses and disclosures of protected health information that may be made by the Division and of the individual/responsible person's rights and the Division's legal duties with respect to the protected health information.

The Division must provide a copy of the Notice of Privacy Practices (Appendix 1500.I), upon request, to any person, however, the Division is not required to provide a Notice of Privacy Practices (Appendix 1500.I) to any individual who is an inmate of a correctional facility.

The Division must promptly revise and distribute its Notice whenever there is a material change to the uses or disclosures, the individual's

rights, the Division's legal duties, or other privacy practices stated in the Notice of Privacy Practices (Appendix 1500.I).

The Division must provide the Notice of Privacy Practices (Appendix 1500.I) at the time of enrollment to individuals/responsible person(s) who are new enrollees and will have them sign an acknowledgement of receipt of the Notice.

No less frequently than once every three (3) years, the Division must notify individuals of the availability of the Notice and how to obtain the Notice.

The Division must have the Notice of Privacy Practices (Appendix 1500.I) available at all physical service delivery sites including Intermediate Care Facilities for the Cognitive Disabled, group homes and day programs. In day programs, the Notice must be posted in a clear and prominent location where it is reasonable to expect individuals seeking service from the Division to be able to read the Notice. In Intermediate Care Facilities for the Cognitive Disabled and group homes, the Notice will be kept in each individual's record.

Copies of the Notice of Privacy Practices (Appendix 1500.I) must also be kept at each physical service delivery site for individuals or their responsible person(s) to take with them.

The Division may provide the Notice of Privacy Practices (Appendix 1500.I) to an individual/responsible person by electronic mail if the individual/responsible person agrees to electronic notice and such agreement has not been withdrawn. If the transmission of the electronic mail fails, a paper copy of the Notice must be provided to the individual/responsible person. The individual/responsible person who is the recipient of electronic Notice retains the right to obtain a paper copy of the Notice from the Division upon request.

#### 1505.2 Uses and Disclosures of Protected Health Information - Where No Authorization Is Needed

Protected health information may be used and disclosed by the Division and others outside of the Division who are involved in a person's care and treatment when providing health care services to them. Protected health information may also be used and disclosed for the purpose of paying health care bills and to support the operations of the Division.

The following are examples of the types of uses and disclosures of protected health information that the Division is permitted to make. These examples are not meant to be exhaustive, but to describe the types of uses and disclosures that may be made by the Division.

a. Treatment:

The Division will use and disclose protected health information to provide, coordinate, or manage health care and any related services. This includes the coordination or management of a person's health care with a third party who has already obtained that person's permission to have access to their protected health information. For example, the Division would disclose protected health information, as necessary, to a health plan that provides care. The Division will also disclose protected health information to physicians who may be treating a person. Protected health information may be provided to a physician to whom a person has been referred to ensure that the physician has the necessary information to diagnose or treat them.

In addition, the Division may disclose protected health information to another physician or health care provider, e.g., a specialist or laboratory, who, at the request of a person's physician, becomes involved in their care, diagnosis or treatment.

b. Payment:

Protected health information will be used, as needed, to obtain payment for health care services. This may include certain activities that a health insurance plan may undertake before it approves or pays for the health care services the Division recommends for a person such as: making a determination of eligibility or coverage for insurance benefits; reviewing services provided to a person for medical necessity; and undertaking utilization review activities. For example, obtaining approval for a hospital stay may require that relevant protected health information be disclosed to the health plan to obtain approval for the hospital admission.

c. Healthcare Operations:

The Division may use or disclose, as needed, protected health information in order to support the business activities of the Division. These activities include, but are not limited to, quality assessment activities, employee review activities, training of staff, licensing, research, resolving grievances and conducting or arranging for other business activities.

For example, the Division may disclose protected health information to the Arizona Health Care Cost Containment System for quality assurance purposes or to obtain reimbursement for health care services provided.



The Division will share protected health information with third party "business associates" that perform various activities, e.g., residential services, day program services, home and community based supports and services, for the Division. Whenever an arrangement between the Division and a private business associate involves the use or disclosure of protected health information, the Division will have a written contract with the business associate that contains terms that will protect the privacy of your health information. If the business associate is required by law to provide the service, the Division will obtain written assurance that the entity or individual will safeguard the privacy of protected health information.

The Division may use or disclose protected health information, as necessary, to provide a person with information about treatment alternatives or other health-related benefits and services that may be of interest to the person. That person may contact the Division's Privacy Officer to request that these materials not be sent to them.

1505.3      Other Permitted and Required Uses and Disclosures That May Be Made Without Authorization or Opportunity to Object

The Division may use or disclose protected health information in the following situations without authorization. These situations include:

a.      Required By Law:

The Division may use or disclose protected health information to the extent that the use or disclosure is required by law. The use or disclosure will be made in compliance with the law and will be limited to the relevant requirements of the law. The person will be notified, as required by law, of certain uses or disclosures.

b.      Public Health:

The Division may disclose protected health information for public health activities and purposes to a public health authority that is permitted by law to collect or receive the information. The disclosure will be made for the purpose of controlling disease, injury or disability. The Division may also disclose protected health information, if directed by the public health authority, to a foreign government agency that is collaborating with the public health authority.

c. Communicable Diseases:

The Division may disclose protected health information, if authorized by law, to a person who may have been exposed to a communicable disease or may otherwise be at risk of contracting or spreading the disease or condition.

d. Health Oversight:

The Division may disclose protected health information to a health oversight agency for activities authorized by law, such as audits, investigations and inspections. Oversight agencies seeking this information include government agencies that oversee the health care system, government benefit programs, other government regulatory programs and civil rights laws.

e. Abuse or Neglect:

The Division may disclose protected health information to a public health authority that is authorized by law to receive reports of abuse or neglect. If the Division reasonably believes that a person has been a victim of abuse, neglect or domestic violence, the Division may disclose your protected health information to a government authority authorized to receive reports of abuse, neglect or domestic violence. This includes disclosures to Child Protective Services, Adult Protective Services, local law enforcement agencies and the Attorney General's Office. The information will be disclosed when the person agrees to the release of the information or the disclosure will be made consistent with the requirements of applicable federal and state laws including protections afforded a person to prevent serious harm.

f. Food and Drug Administration:

The Division may disclose protected health information to a person or company required by the Food and Drug Administration to report adverse events, product defects or problems, biologic product deviations, or to track products; to enable product recalls; to make repairs or replacements; or to conduct post marketing surveillance, as required.

g. Criminal Activity:

Consistent with applicable federal and state laws, the Division may disclose protected health information if a person is the victim of a crime or the Division believes that the use or disclosure is necessary to prevent or lessen a serious and imminent threat to the health or safety of a person or the public. The Division may also disclose

protected health information if it is necessary for law enforcement authorities to identify or apprehend an individual.

h. Law Enforcement:

The Division may also disclose protected health information, so long as applicable legal requirements are met, for law enforcement purposes. These law enforcement purposes include:

1. legal processes as otherwise required by law;
2. limited information requests for identification and location purposes;
3. gathering information pertaining to victims of a crime;
4. suspicion that death has occurred as a result of criminal conduct;
5. gathering information in the event that a crime occurs at a person's residence; and
6. a medical emergency and it is likely that a crime has occurred.

i. Legal Proceedings:

The Division may disclose protected health information in the course of any judicial or administrative proceeding, in response to an order of a court or administrative tribunal (to the extent such disclosure is expressly authorized), and in certain conditions in response to a subpoena, discovery request or other lawful process.

j. Inmates:

The Division may use or disclose protected health information if a person is an inmate of a correctional facility.

k. Coroners, Funeral Directors and Organ Donation:

The Division may disclose protected health information to a coroner or medical examiner for identification purposes for determining cause of death or for the coroner or medical examiner to perform other duties authorized by law. The Division may also disclose protected health information to a funeral director, as authorized by law, in order to permit the funeral director to carry out necessary duties. The Division

may disclose such information in reasonable anticipation of death. Protected health information may be used and disclosed for cadaveric organ, eye or tissue donation purposes.

I. Research:

The Division may disclose protected health information to researchers when their research has been approved by an institutional review board that has reviewed the research proposal and established protocols to ensure the privacy of a person's protected health information.

1505.4 Uses and Disclosures of Protected Health Information - Based Upon Written Authorization

Other uses and disclosures of protected health information will be made only with written authorization unless otherwise permitted or required by law as described below. An individual/responsible person may revoke their authorization, at any time, in writing, except to the extent that their health care provider has taken an action in reliance on the use or disclosure indicated in the authorization. If indicated, the Division's Privacy Officer will insure that the protected health information is redacted before release.

a. Other Permitted and Required Uses and Disclosures That May Be Made With Authorization or Opportunity to Object

The Division may use and disclose protected health information in the following instances. An individual/responsible person has the opportunity to agree or object to the use or disclosure of all or part of their protected health information. If the individual/responsible person is not present or able to agree or object to the use or disclosure of the protected health information, the Division may, using the professional judgment of its staff, determine whether the disclosure is in the person's best interest. In this case, only the protected health information that is relevant to a person's health care will be disclosed.

b. Others Involved in a Person's Healthcare:

Unless an individual/responsible person objects, the Division may disclose to a member of their family, a relative, a close friend or any other person identified, their protected health information that directly relates to that person's involvement in the person's health care or payment of that health care. The Division must obtain written authorization to disclose protected health information to prospective providers. If the individual/responsible person is unable to agree or objects

to such a disclosure, the Division may disclose such information as necessary if the Division determines that it is in their best interest based on Division staff's professional judgment. The Division may use or disclose protected health information to notify or assist in notifying a family member, personal representative or any other person that is responsible for the person's care of their location, general condition or death. Finally, the Division may use or disclose protected health information to an authorized public or private entity, to assist in disaster relief efforts and to coordinate uses and disclosures to family members or other individuals involved in a person's health care.

c. Emergencies:

The Division may use or disclose protected health information in an emergency treatment situation involving the person or for such emergencies as disaster relief.

1505.5 Rights

The following is a statement of an individual/responsible person's rights with respect to protected health information and a brief description of how a person may exercise these rights.

- a. An individual/responsible person has the right to inspect and copy protected health information. This means the individual/responsible person may inspect and obtain, upon written request, a copy of protected health information that is contained in the case record, for as long as the Division maintains the protected health information. Per Arizona Revised Statute § 12-351, the Division may charge for copies and the time to locate and prepare the information for disclosure. The Division has 30 calendar days to honor an individual's request to inspect and copy their protected health information. The Division's Privacy Officer will verify the status of the responsible person before disclosing protected health information.

The Division's Privacy Officer may deny access to protected health information if the disclosure of the information is reasonably likely to endanger the life or physical safety of the individual. The individual has the right to have the denial reviewed by the Division's Medical Director.

Under federal law, however, a person may not automatically inspect or copy the following records:

1. psychotherapy notes;

2. information compiled in reasonable anticipation of, or use in, a civil, criminal, or administrative action or proceeding; and
  3. protected health information that is subject to law that prohibits access to protected health information. In some circumstances, a person may have a right to have this decision reviewed. Contact the Division's Privacy Officer if you have questions about access to records.
- b. A person has the right to request a restriction of their protected health information. This means the person may ask the Division not to use or disclose any part of their protected health information for the purposes of treatment, payment or health care operations. A person may also request that any part of their protected health information not be disclosed to family members, relatives or friends who may be involved in their care or payment for their care, or for notification purposes as described in the Notice of Privacy Practices (Appendix 1500.I). Their request must state the specific restriction requested and to whom they want the restriction to apply.
- c. The Division is not required to agree to a restriction that a person may request. If the Division believes it is in the person's best interest to permit use and disclosure of their protected health information, their protected health information will not be restricted. If the Division does agree to the requested restriction, the Division may not use or disclose their protected health information in violation of that restriction unless it is needed to provide emergency treatment; even then the Division will request that the information not be further disclosed. The person may request a restriction by submitting the request in writing to the Division's Privacy Officer at Central Office.

The Division may terminate the agreement to a restriction if the person agrees to or requests the termination of the restriction in writing.

The Division may terminate the agreement to a restriction if the person orally agrees to the termination and the oral agreement is terminated.

The Division may terminate the agreement to a restriction if the Division informs the person that it is terminating its agreement to a restriction except that such termination is only effective with respect to protected health information created or received after it has so informed the person.

- d. A person has the right to request to receive confidential communications from the Division by alternative means or at an alternative location. The Division will accommodate reasonable requests. The Division may also condition this accommodation by asking the person to specify an alternative address or other method of contact. The Division will not request an explanation from the person as to the basis for the request. This request must be made in writing to the Division's Privacy Officer.
- e. A person may have the right to have their protected health information amended. This means the person may request an amendment of protected health information about them the Division created in a case record for as long as the Division maintains this information. This statement must provide a reason to support the requested amendment. The Division has 60 days from receipt of the request to act upon it or state in writing that up to a 30 day extension is needed, the reason(s) for the delay and the anticipated due date for a written response. Any amended protected health information will be noted as such. Upon the completion of the amendment, all appropriate parties, including business associates, will be notified of the change(s). In certain cases, the Division may deny a request for an amendment. If the Division denies the request for amendment, the person has the right to file a statement of disagreement with the Division's Privacy Officer. If the Division continues to deny the request, it may prepare a rebuttal to the statement; the Division will provide the person with a copy of any such rebuttal.
- f. A person has the right to receive an accounting of certain disclosures the Division has made, if any, of protected health information. This right applies to disclosures for purposes other than treatment, payment or health care operations as described in the Notice of Privacy Practices (Appendix 1500.I). It excludes disclosures authorized by the person or which the Division may have made to the person, to family members, relatives or friends involved in the person's care, as well as any releases authorized by federal law or required by law. The person has the right to receive specific information regarding these disclosures that occurred after April 14, 2003. The person may request a shorter timeframe. The right to receive this information is subject to certain exceptions, restrictions and limitations.

The person's Support Coordinator will maintain an access log in the individual's record that lists all disclosures made by the Division outside of those listed above (Appendix 1500.I). The Division must act on the individual's request for an accounting no later than 60 days after receipt of the request. The Division must temporarily suspend any

individual's right to receive an accounting of disclosures to a health oversight agency or law enforcement official for the time specified by such agency or official, if such agency or official provides the Division with a written statement that such an accounting to the individual would be reasonably likely to impede the agency's activities and specifying the time for such a suspension is required.

- g. Consumers have the right to obtain a paper copy of the Notice of Privacy Practices (Appendix 1500.I) from the Division, upon request, even if the person has agreed to accept that notice electronically.
- h. The individual/responsible person will identify, through the Individual Support Plan process, the person's to whom staff members may disclose protected health information.

#### 1505.6 Complaints

A person may complain to the Division or to the Secretary of Health and Human Services if they believe their privacy rights have been violated by the Division. They may file a written complaint with the Division by sending it to the Division's Privacy Officer. The Division will not retaliate against the person for filing a complaint.

A complaint must be filed in writing, either on paper or electronically. The complaint must describe the act(s) believed to be in violation of HIPAA requirements. A complaint must be filed within 180 days of when the complainant knew or should have known that the act or omission complained of occurred.

A person may choose to file the complaint directly with the U.S. Department of Health and Human Services. The written complaint can be mailed to:

Office for Civil Rights  
Medical Privacy, Complaint Division  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
HHH Building, Room 509H  
Washington, D.C. 20201

Or, the complaint can be sent electronically to:

ocrmail@hhs.gov

When a Health Insurance Portability and Accountability Act complaint is communicated to any workforce member, that workforce member shall immediately notify the Division's Privacy Officer and shall inform the complainant of the name and contact information of the Division's Privacy Officer. The Division's Privacy Officer will notify the District



Program Administrator/Manager or designee, of the complaint and will request that the appropriate District representative investigate the complaint. A report of findings will be forwarded to the Division's Privacy Officer no later than 90 days from the date of the complaint.

The Division's Privacy Officer will give the complainant information about his/her right to file a complaint with the U.S. Secretary of Health and Human Services.

The Division's Privacy Officer shall document all complaints received, and their disposition, if any.